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March 2, 2016

Legislative Office Building 300 Capitol Avenue, Suite 1 Hartford, CT 06106-1567

Senator Gerratana, State Representative, Ritter other Public Committee Members and all here today.

My name Robert Fiore, I am the President and Founder of the Connecticut Epilepsy Advocate, Inc. which is a recognized 501 (c) (3) Non-Profit Organization. For the record I am a resident of Milford and I have Epilepsy my entire life.

I am here to submit my testimony for Bill Number 5450 - AN ACT CONCERNING THE PALLIATIVE USE OF MARIJUANA.

Respectfully

Robert A. Fiore President and Founder

Connecticut Epilepsy Advocate, Inc.

...Progress Through Awareness

www.ct-ea.org

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# Written Testimony of Robert A. Fiore Connecticut Epilepsy Advocate, Inc. March 2, 2016 Joint Committee on Public Health

#### BIII Number 5450 - AN ACT CONCERNING THE PALLIATIVE USE OF MARIJUANA.

My name is Robert Fiore and I am the President and Founder of the Connecticut Epilepsy Advocate, Inc. We are a recognized 501 (c) (3) Non-Profit Organization which serves the entire State. For the record I am a resident of Milford and I have suffered with Epilepsy my entire life.

I am here to speak in favor of House Bill number 5450. The purpose of this bill is to make cannabis oil available to children living with Epilepsy. For the record we are aware this Bill also addresses other medical conditions, however, today I will be specifically addressing epilepsy.

We are convinced that children here in Connecticut living with Lennox Gastaut Syndrome (LGS), Dravet Syndrome, and very severe general Epilepsy stand to gain tremendously from this legislation. Here are a few examples of children that have been helped by using the correct cannabis oil:

- Ruiz was having 3,000 seizures a month, approximately 100 a day and since taking cannabis oil has gone down to 1 or 2 a month
- Charlotte went from 1,200 seizures a month down to 2 or 3 a month
- Hailey went from 1,250 seizures a month down to 734 and the number continues to get lower
- Carolina went from 110 seizures in one month down to 20 to 25 a month

(Please understand that due to patient privacy concerns we cannot give their full name or place of residence)

For the record I have included a document titled: "Doctors' Statements of Support for Medical Cannabis for Epilepsy" from Lisa Smith, which offers a wealth of information from numerous doctors.

We are also requesting that the Tetrahydrocannabinol (THC) levels should be no more than 0.3% (three-tenths of a percent). We feel it is safer for people to start at a low level and then increase it if necessary.

We would like to suggest that the title of the legislation should be changed to read: "An Act Concerning the Palliative Use of Cannabis Oil", this way there will be no confusion or negative connotations. Yes, there is a difference!

In conclusion I strongly urge you to pass this bill, which will help the many Connecticut children suffering from the various forms of Epilepsy I have mentioned. The many previous requests to pass Bills like this one should give you a clue as to the dire need for this legislation, which will have so many positive effects, and according to our best science, no negative ones.

I thank you for your time today and I will gladly answer any questions you might have.

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#### Doctors' Statements of Support for Medical Cannabis for Epilepsy

## Oct, 2013 Dr. Catherine Jacobson, Post-Doctoral Scholar in Neurology, Stanford University & UCSF

"CBD appears to be an effective AED in a very difficult-to-control pediatric population of epilepsy. Importantly, it is reported to be extremely well tolerated."

"I feel very strongly that, in this case, CBD does not belong in the same Scheduled category as Heroin."

#### Nov 11, 2013 Dr. Francis Filloux, M.D. Chief, Division of Neurology, University of Utah.

"Cannabidiol (CBD) is on of the "cannabinoids" or naturally occurring chemical elements found in the natural product cannabis, or marijuana. There is extensive "pre-clinical" data, (meaning experimental data in animals and laboratory studies) that indicated CBD as a chemical is effective in reducing epileptic activity.... Thus, there is extensive and reproducible data demonstrating that, from an experimental point of view, CBD holds great promise as an anti-epileptic agent."

## Nov 18, 2013 Brandon A. Zielinski, MD, PhD, Division of Pediatric Neurology, University of Utah School of Medicine

As a pediatric neurologist who cares for many children with severe epilepsy, I believe this product (cannabidiol), one that is currently legally available in the United States (Colorado) and is legally taken by some of our citizens, should be available to children in Utah with severe epilepsy."

# April 2013. Dr. Elizabeth Thiele, Director of Pediatric Epilepsy Program, Massachusetts General Hospital.

"Based on a review of the literature and first-hand experience treating pediatric epilepsy patients, it is my opinion that medical marijuana—and, particularly, the non-psychoactive ingredient in medical marijuana, cannabidiol (CBD)—may have substantial medical benefit for pediatric epilepsy patients, as well as significantly fewer adverse side effects than many of the other anti-epileptic therapies available today."

### Dr. Orrin Devinsky, Director of Comprehensive Epilepsy Center, NYU Langone Medical Center

"Cannabis can play a role in helping children with epilepsy."

#### Dr. Margaret Gedde, General Practitioner, Colorado

"Patients are seeing between 50 and 90 percent reduction in seizures with no side effects. That's amazing."